# Disability and Health 2013 Annual Report















Rhode Island Department of Health Disability & Health Program Office of Special Health Care Needs

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#### Introduction

The Rhode Island Department of Health (HEALTH) is a diverse and interactive state agency with broad-ranging public health responsibilities whose primary mission is to prevent disease, and protect and promote the health and safety of the people of Rhode Island. While communicable disease control, vital records, environmental health and other functions carry on Rhode Island's public health traditions established over 150 years ago, newer and equally important faction's of today's public health landscape provide greater opportunities for HEALTH to carry out its mission and to reach its vision: *All people in Rhode Island will have the opportunity to live a safe and healthy life in a safe and healthy community*.

HEALTH's Division of Community Family Health and Equity (DCFHE) aims to achieve health equity for all populations, through eliminating health disparities, assuring healthy child development, preventing and controlling disease and disability, and working to make the environment healthy. The Division's six teams (Health Disparities and Access to Care; Healthy Homes and Environment; Chronic Care and Disease Management; Health Promotion and Wellness; Perinatal, Early Childhood, and Adolescent Health; Preventative Services and Community Practices) promote synergy, collaboration, and coordination among programs with the goal of achieving health equity. The Health Disparities and Access to Care Team within DCFHE, is organized to address populations experiencing health disparities as a result of race or ethnicity, education, gender, sexual orientation, language, disability status, geographic location or any combination of these characteristics.

HEALTH's Disability and Health Program (DHP), based within the Health Disparities and Access to Care Team, has been charged with facilitating the promotion of health and wellness of Rhode Islanders with special needs, disabilities and chronic conditions along with reducing health

disparities between Rhode Islanders with disabilities and Rhode Islanders without disabilities. With a grant from the federal Centers for Disease Control and Prevention (CDC) and Title V, Maternal and Child Health funds from the federal Department of Health and Human Services, the DHP has initiated several efforts under its charge including reinforced policy and sustainability; health promotion; and emergency preparedness.

## What is a Disability?

The World Health Organization (WHO) characterizes "Disability" as an umbrella term for impairments, activity limitations or participant restrictions<sup>1</sup>. An impairment is a problem in body function or structure; an activity limitation is a difficulty encountered by an individual in executing a task or action; while a participation restriction is a problem experienced by an individual in involvement in life situations<sup>1</sup>. Disability is thus not just a health problem. It is a complex phenomenon, reflecting the interaction between features of a person's body and features of the society in which he or she lives<sup>1</sup>. Disabilities can affect people in different ways, even when one person has the same type of disability as another person.

Many survey tools use multiple questions to examine disability status and these questions can vary depending on the data source. The Behavioral Risk Surveillance System (BRFSS)<sup>2</sup> considers an individual to have a disability if the respondent answers yes to either of the following self-reported questions "Are you limited in any way in any activities because of physical, mental or emotional problems?" and/or "Do you now have any health problem that requires you to use special equipment, such as a cane, a wheelchair, a special bed, or a special telephone?"

<sup>2</sup> http://www.cdc.gov/brfss/

<sup>&</sup>lt;sup>1</sup>WHO (2000). International classification of functioning, disability and health. WHO:Geneva

The Youth Risk Behavioral System (YRBS)<sup>3</sup> classifies public high school students as having a disability is they respond yes to either of the following self-reported questions "Do you have any physical disabilities or long-term health problems? (Long-term means 6 months or more.)." and/or "Do you have any long-term emotional problems or learning disabilities? (Long-term means 6 months or more.)."

# Who are People with Disabilities<sup>4</sup> in Rhode Island?

The DHP uses resources from Rhode Island's BRFSS<sup>5</sup> and YRBS<sup>6</sup> to monitor the prevalence and trends of disabilities, identify populations at risk, measure health disparities between Rhode Islanders with and without disabilities and develop programs with appropriate evaluation measures.

Table 1 presents Demographic Characteristics among Rhode Island Adults (Ages 18-64) with Disabilities in 2010. Overall 18 % of Rhode Islanders reported having a disability. Males and females experience disability at almost equal rates (18 % male vs. 17% female). Disability status among veterans and non-veterans was 24% and 17% respectively. PWD represent 18% of white, non-Hispanic populations, 12% of Hispanic populations and 18% of other, non-Hispanic populations. Among PWD 22% completed high school or less, 22% completed some college and 12% are college graduates. Household incomes below \$25,000 were most prevalent (32%), followed by household incomes \$25,000 to \$49,999 (19%) and lastly household incomes \$50,000 and above (12%) for PWD.

Data suggest that disparities exist between Rhode Island adult PWD and adult PWOD in the areas of health risks and behaviors, prevention and screenings, general health conditions, and chronic conditions. For health risks and behaviors, PWD are more likely to be obese (38%) than PWOD (24%) and live sedentary life styles, defined as no leisure physical activity in past month, (35% vs. 19%). Unfortunately, a large disparity exists for smoking status with PWD being twice as likely to currently

<sup>&</sup>lt;sup>3</sup> http://www.cdc.gov/yrbs/

<sup>&</sup>lt;sup>4</sup>The following sections will abbreviate People with Disabilities as "PWD" and People without Disabilities as "PWOD"

<sup>&</sup>lt;sup>5</sup> http://www.health.ri.gov/publications/healthriskreports/adults/2010Disability.pdf

<sup>&</sup>lt;sup>6</sup> http://www.health.ri.gov/publications/healthriskreports/youth/2011Disability.pdf

smoke as PWOD (30% vs. 15%). PWD are also more likely to report dissatisfaction with life (17% vs. 4%) and insufficient social/emotional support (27% vs.17%) than their PWOD counterparts. For prevention and screening indicators large disparities exist for having a mammogram in the past 2 years for women aged 40-64 (25% vs. 16%) and visiting a dentist in the past year (30% vs.19%). Also, PWD report more often than PWOD as being uninsured (15% vs. 11%) and having no routine checkup in the past year (21% vs.26%). Many of the largest disparities exist for indicators of general health and chronic conditions. PWD are more than seven times as likely to report that there general health is fair or poor (37% vs. 5%). PWD are more likely to suffer from coronary heart disease (7% vs. 1%), asthma (25% vs. 8%) and diabetes (13% vs. 4%).

Table 1. Demographic Characteristics among Rhode Island Adults (Ages 18-64) with Disabilities in 2010

Demographic Characteristic	People with Disabilities
Overall	18%
Age	
18-24 years	12%
25-44 years	12%
45-64 years	25%
Sex	
Male	18%
Female	17%
Race/Ethnicity	
White, non-Hispanic	18%
Hispanic	12%
Other, non-Hispanic	18%
Veteran Status	
Veteran	24%
Non-veteran	17%
Educational Level	
High school or less	22%
Some college	22%
Graduated college	12%
Income level*	
< \$25,000	32%
\$25,000 to \$49,000	19%
\$50,000+	12%

Source: 2010 Rhode Island Behavioral Risk Factor Survey (n=6,599)

<sup>\*</sup>Annual household income

In 2011 over 25% of Rhode Island public high school students had a disability. These students were in greater jeopardy from many risk behaviors compared with their peers without a disability. Like adults with disabilities students with disability are more likely to be obese (13% vs. 10%), lack exercise (62% vs. 48%) and currently smoke (18% vs. 8%) than their peers without a disability. Students with a disability were more likely to report having unprotected sex (50% vs. 35%), drinking and driving (11% vs. 4%) and binge drinking (25% vs. 17%).

## What Have We Accomplished?

HEALTH's Disability and Health Program promotes health and wellness of Rhode Islanders with special needs, disabilities and chronic conditions along with reducing health disparities between Rhode Islanders with disabilities and Rhode Islanders without disabilities. With a grant from CDC and Title V the DHP has initiated several efforts under its charge including reinforced policy and sustainability; health promotion; and emergency preparedness.

The DHP is an active participant in HEALTH's **Community Health Network** which is a collaborative of health and wellness programs within the Division of Community, Family Health, and Equity and community agencies serving individuals with chronic conditions. The committee developed the Chronic Condition Education & Self-Management Program of evidence based courses and service intended to equip people in managing their disability or chronic condition. The DHP contracted with the state's two independent living centers to promote enrollment of people with disabilities.

The **Tobacco Control Program** presented to youth with disabilities at the Office of Special Needs Youth Advisory Committee and Dare to Dream Student Conference on the dangers of smoking, cessation strategies and tobacco company marketing strategies. Further, peer resource specialists who work with PWD of all ages were trained in smoking cessation programs, resources and supports.

The DHP benefited from the resources and expertise of the **Childhood / Adolescent Immunization Program** through a presentation of vaccinate before you graduate to youth with disabilities being trained as "Youth Health Coaches".

The DHP participated in the **school nurse teacher's annual conference** in May that had over 200 participants. Each participant received the CDC information "Health Care Provided: How to Include People with Disabilities" and "People with Disabilities: Tips for Healthy Living".

The DHP partnered with the Family Planning Program on the **Preconception Health Strategic Plan** through facilitating feedback sessions with youth with disabilities and their families, revising final products, and assistance in dissemination. Through DHP's involvement, youth with disabilities participated on the conference panel where Rhode Island's preconception health strategic plan was unveiled. Further, each participant received the CDC information "Health Care Provided: How to Include People with Disabilities" and "People with Disabilities: Tips for Healthy Living".

The DHP reviewed and proposed edits to the **Rhode Island Comprehensive Cancer Strategic Plan** to include specific outreach and education of healthcare practitioners on the screening and treatment of PWD. These recommendations will be vetted with the Comprehensive Cancer Advisory Committee.

The **Women's Cancer Screening Program** provided the DHP with a list of mammography facilities in Rhode Island in order to distribute the CDC's "Right to Know" Campaign materials. The DHP will be surveying the accessibility of the mammography facilities during the summer of 2013. The DHP provided resources to the participants of the Breast Imaging Seminar at their annual meeting in May 2013. Each participant received the CDC information "It's your life. No one can protect it better than you".

The **Oral Health Program** had a Special Needs Dentistry Mini- Residency attended by 150 participants and addressed the unique needs of PWD accessing dental services. Each participant received the CDC information "Health Care Provided: How to Include People with Disabilities" and "People with Disabilities: Tips for Healthy Living".

In May 2013, the **Center for Public Health Communication** modified its images policy to include the following: "It is important to include images of persons with a variety of disabilities in HEALTH communications. Persons with disabilities can include: blind / visually impaired; person who uses a wheelchair; person with autism; person of short stature; person with Down Syndrome; person who is deaf; person with physical disability. Whenever possible, images should demonstrate positive health behaviors and positive, non-stereo typical images of people with disabilities." The DHP purchased professional quality images of PWD for HEALTH's library of stock images and will consult on image selection.

The DHP contracted with Accessible Healthcare RI to conduct accessibility assessments and provide educational materials to licensed health care facilities in Rhode Island. The assessments adhere to the Americans with Disabilities Act (ADA) guidelines and promote universal design and inclusiveness in all aspects of screening protocol. Accessible Healthcare RI conducted training of 29 under-graduate students in nursing, physical therapy, and occupational therapy to serve as accessibility assessors. Accessible Healthcare RI provided information on the requirements of ADA and on the available tax credits for creating access to more than 50 licensed healthcare facilities surveyed.

The DHP conducted targeted outreach to health care facilities that serve PWD in the State's Medicaid Program. Outreach letters were mailed to 200 health care facility providers regarding education/outreach for accessibility assessment.

The DHP is engaged in developing an online searchable database identifying accessible features of facilities and medical services for persons with special needs, disabilities, and chronic conditions.

#### **SPOTLIGHT:** Healthy Lifestyles for People with Disabilities

Healthy Lifestyles for People with Disabilities was developed by the Oregon Office on Disability & Health. It is a 16 hour evidence based curriculum designed to help people develop confidence and skills to stay on a journey toward a healthy happy life.

Participants learn how to manage their own health and find balance with all aspects of health including emotional health, physical health, meaningful activities, social health and spiritual health. Healthy Lifestyles is a fun, interactive 3 day workshop presented by a certified Youth Health Coach and an adult trainer.

The DHP has made **Healthy Lifestyles workshops** available to young adults with disabilities ages 18-30 since Fall 2012. In that time, the DHP has trained 28 youth presenters, 76 young adults completed the 16 hour workshop, and made 9 Healthy Lifestyles outreach informational presentations. Healthy Lifestyles workshops include incentives for participation and a comprehensive evaluation.

The DHP is partnering with several agencies and groups concerning Healthy Lifestyles, namely Foster Forward (formerly Foster Parent Association), Rhode Island Parent Information Network, Rhode Island Department of Labor and Training, YMCA, Coastal Medical Physician Education Program, Sherlock Center for Disabilities, Rhode Island Regional Transition Academies, District Wellness Committees, Youth Advisory Committee, Rhode Island Department of Education, Executive Office of Health and Human Services, Gamm Theatre, and Dare to Dream Student Leadership Development.

The DHP collaborates with HEALTH's **Center for Emergency Preparedness and Response (CEPR)** and other public and private entities to develop a statewide coordinated emergency preparedness system. Public and private entities include: the Rhode Island Emergency

Management Agency (RIEMA), the Domestic Preparedness Subcommittee of the Lt. Governor's Emergency Management Advisory Council, the American Red Cross of Rhode Island, and others to plan for and respond to emergencies throughout the state. The DHP conducted a review of the State Emergency Operations Plan (SEOP) for inclusion of PWD in emergency planning and response and compliance with the ADA.

The DHP and CEPR planned, developed, and facilitated two **First Responder Emergency Preparedness Trainings** for fire and police personnel. The trainings were held in April 2013 and attended by over 150 first responders representing police, fire, emergency management services (EMS), and emergency management agency (EMA) organizations in the state. First Responders were provided with an overview of Autism Spectrum Disorder (ASD) behavioral symptoms, educated about effective communication techniques, and provided practical skills to safely interact with persons with ASD or language disabilities during an emergency.

The DHP and CEPR developed an **Emergency Communication Board** to help facilitate communication with those who are unable to speak during an emergency. The tool is being tested spring and summer 2013 with the hopes of a full launch across the state to any partners interested in using it.

A youth preparedness training program entitled **Disaster Readiness Actions for Teens (DRAT)** has been scheduled for presentation to youth with disabilities during a summer youth program. The program was researched and planned to address the goal of engaging, educating, and empowering youth to respond safely during community critical incidents such as natural disasters, man-made incidents, public health emergencies, and school threats. The training is segmented into 6 modules, each addressing a separate area of emergency preparedness.

#### **SPOTLIGHT: Rhode Island Special Needs Emergency Registry (RISNER)**

The Rhode Island Department of Health and the Rhode Island Emergency Management
Agency joined together to develop a registry for Rhode Islanders with disabilities, chronic
conditions, and other special healthcare needs. The **Rhode Island Special Needs Emergency Registry (RISNER)** with a current enrollment of 11,698 is designed to
identify individuals who may require special assistance during emergencies. Enrollment
in the Registry does not guarantee assistance, but allows first responders to appropriately
plan for, prepare for, and respond to the needs of the community.

#### RISNER Outreach Activities:

- Four part-time outreach workers were employed to provide education about emergency preparedness and utilization of the emergency registry in accordance with the outreach plan.
- ☑ Outreach workers also provide education to municipal leadership (police, fire, EMA, and EMS) regarding utilization of the registry system to facilitate promotion of the registry within their municipalities.
- ☑ Attendance with a promotion table at most major summer events (fairs, festivals, etc.) in Rhode Island.
- ☑ Sponsored an NCCC Americorp team to conduct RISNER outreach through several means including: door to door outreach and tables at municipal events, senior centers, and high rises.
  - 5,000 people received emergency preparedness kits
- ☑ American Red Cross shelters.
- ☑ RISNER was highlighted on local TV news with a staffed call bank to answer questions and enroll individuals.

- ☑ 10,343 letters were sent out to RISNER enrollees to update the registry as well as promote personal preparedness.
- ✓ Hurricane Sandy increased registration when over 600 people registered in the days preceding the storm as RISNER was highlighted by local and regional news outlets.
- ☑ Nemo Blizzard increased registration by almost 200 in the days preceding the storm and throughout the blizzard weekend as RISNER was highlighted by local and regional news outlets.
- ☑ 169 events had a RISNER outreach table or speaker (including events mentioned above).
- ☑ All RISNER partners were alerted to the free immunization opportunities sponsored by HEALTH to encourage PWD to attend.
- All Resident Service Coordinators and school nurses were trained on RISNER to outreach to their appropriate populations.
- ☑ Partnerships were established with Durable Medical Equipment providers, Meals on Wheels, home health care agencies, and dialysis centers to provide RISNER enrollment forms to all of their customers.

## Staff of Rhode Island's Disability & Health Program

Deborah Garneau, Office of Special Needs Chief, Interim Team Lead Health Disparities & Access to Care Team

Colleen Polselli, Disability & Health Program Manager

Deb Golding, Adolescent Healthcare Transition Coordinator

Carmen Boucher, Disability & Health Program Assistant

Pauline Thompson, Youth Resource Specialist

Elisabeth Becker, Health Disparities & Access to Care Team Evaluator

Kathleen Kuiper, Peer Resource Specialist Program Manager

James Coyne, Center for Emergency Preparedness and Response

The DHP staffs and convenes the **Disability Community Planning Group (DCPG)** to advise the program on policy and program initiatives, to contribute to and approve the strategic plan, and to oversee the integration of people with disabilities into state public health programs. The membership of the DCPG consist of people with various disabilities, parents and caregivers of children with disabilities, staff of community disability serving agencies, and representatives of state human service agencies. The composition of the DCPG is at least 51% person / caregiver with a disability. The DCPG meets quarterly.

Pauline Thompson

# **Disability Community Planning Group Members**

Janet M. Iovino Marisa Petreccia Brittan Bates-Manni Christina Battista Laura Jones Joanne Ouinn Dawn Brew Darren Kaw Lorna Ricci Sharon Kernan Corrina Roy Leo Canuel Benvinda Santos Paul Choquette Laurie Leonard **Bob Cooper** Lisa Schaffran Tom Martin James Gillen Jane Slade Kate McCarthy-Barnett

Barbara Mulligan

Dennis Harvey Jo Ann Nannig

Dona Goldman